

1st EUROPEAN VIRTUAL PULMONARY FIBROSIS PATIENT SUMMIT

REPORT



23rd – 25th April 2021



Introduction

The PF Summit was the **first virtual European Pulmonary Fibrosis event** bringing together patients and caregivers, healthcare professionals, policy makers and industry representatives.

The event was **designed by patients for patients**, offering a unique platform to discuss research, person-centered care, policy and advocacy around Pulmonary Fibrosis (PF) and Interstitial Lung Diseases (ILDs).

The three-day Summit included **15 Sessions and 52 speakers**, covering a wide range of topics including clinical, treatment, self-management and research.



Steve Jones, EU-IPFF President

“Thank you to everybody for working so hard to make the 1st European Pulmonary Fibrosis Summit such a great success. It was amazing to bring together over 300 patients, carers, health care providers, researchers and industry representatives to discuss issues of importance to patients and their families.”



"We would like to wish you good luck for the three-day Summit which beginning in few hours! It is obvious that all of you have worked hard for this interesting agenda concluding so many speakers. We look forward to watching the summit, participating and we are sure that Greece will have a wide and great participation. Thank you for all the immediate support!" (Member of a Patient Organisation)

"Thank you very much! Congratulations to this summit and thank you for all your efforts! The chat function as well as the Swapcard app is gorgeous – I already made some friends." (Patient Advocate)

"Dear all, I just wanted to say thank you and congratulations for putting on an amazing event this weekend. It was very clear that you worked incredibly hard to pull this together and it definitely came off, it was really brilliant." (Industry Representative)

"As a 'young' PF-patient, since 2019, I learned a lot during the last three days. And also for our association for which I am, with three colleagues, preparing a long-term strategy / 'business' plan. I picked up many issues and ideas for that. And also important is the network of Summit friends and sources - also thanks for that!" (Patient & Advocate)

"Congratulations for organizing a very successful summit. My colleague also asked me to send her regards and congratulate and thank you for a great event. We really enjoyed every moment of the event. It was just brilliant, high quality and very well run. We learned a lot and listened attentively to what patients need. After this, you really deserve a good break." (Industry Representatives)

"Thank you so much for making this possible and including this difficult topic in the meeting! You all do a tremendous job!" (Clinician)

"Hello, I am a caregiver for my father with IPF in Rome. Thank you for the Summit and thank you for announcing that in May the EU-IPFF will be making the Sieu Bleu Programme available to patients in the UK and Italy free of charge – I'll keep an eye on social media at the beginning of May. Keep up the good work!" (Carer)

"I just wanted to send you a short note with my congratulations on the EU-IPFF Patient Summit. I attended a few meetings and I think the platform worked easy, the topics were relevant and interesting and you had great speakers! I needed some time to let the information land but I think my favorite was the presentation about including patients in scientific congresses with Pippa Powell and all the ideas she shared of how to include patients at the ERS. I will surely take those ideas to see how we can include patients more in our activities." (Industry Representative)

"Just a quick note to say what a fantastic summit it was and the level of speakers was brilliant. The experience was amazing and the knowledge that I picked up was good. If I was to give a core out of 100, it would be 99. Thanks for a brilliant summit and you were all amazing." (Patient & Advocate)



Summit Attendee Feedback Quotes – A Selection

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Summit Speakers

*Patients/Caregivers · Patient Advocates · Healthcare Practitioners
· Researchers · Pharmaceutical Representatives · Others*



Patient Advocates

Howard Almond (P)
Action Pulmonary Fibrosis UK

Stefano Pavanello (P)
*Unione Trapiantati Polmone -
Padova Representative*

Jean-Michel Fourrier (P)
*EU-IPFF Secretary,
President of APEFPI*

Radostina Getova
EU-IPFF Board Member

Louise Wright
Action for Pulmonary Fibrosis

Raymond Blessing (P)
*The Netherlands Pulmonary
Fibrosis Patients Association*

David Crosby (P)
Irish Lung Fibrosis Association

Steve Jones (P)
*EU-IPFF and Chair, Action for
Pulmonary Fibrosis, UK*

Maxine Flewett (C)
Caregiver

Gergely Meszaros
PHA Europe

Liam Galvin
CEO Secretariat EU-IPFF

Guenther Wanke (P)
Lungenfibrose Forum Austria

Carlos Lines
EU-IPFF President Emeritus

Ron Flewett (P)
Pulmonary Fibrosis Trust Trustee

Klaus Geißler (P)
EU-IPFF Board Member

Chantal Vandendungen (C)
*ABFPI Vice President for
International Relations*

Jan Geissler
Patvocates

Joep Welling (P)
*NVLE - Dutch P.O. for Lupus,
Scleroderma*



Healthcare Practitioners / Researchers

Claudia Valenzuela

Hospital Universitario de la Princesa

Walter Baile

*University of Texas
MD Anderson*

Anna-Maria Hoffman-Vold

Oslo University Hospital

Sabin Handzhiev

Universitätsklinikum Krems

Julia Wälscher

Ruhrlandklinik University Hospital

Andreas Guenther

University Gießen

Wim Wuyts

University Hospital Leuven

Irene Byrne

University Hospital Dublin

Anna Murphy

*University Hospitals of Leicester
NHS Trust*

Ewa Jassem

*University Hospital in Gdańsk,
Poland*

Vincent Cottin

*Louis Pradel University Hospital
and Claude Bernard University*

Sally Singh

*University Hospitals of Leicester
NHS Trust*

Gudrun Kreye

Palliative Care Unit in Krems

Simon Walsh

*National Heart and Lung
Institute Imperial College*

Paolo Spagnolo

University of Padua

Anne-Marie Russell

EU-IPFF Scientific Advisory Board

Paula Ryan

UL Hospitals, Limerick

Katleen Leceuvre

UZ Leuven

Helen Parfrey

Royal Papworth Hospital

Alexander Simidchiev

Association Air For Health

Elisabetta Balestro

University Hospital of Padova

Katarzyna Lewandowska

*National Tuberculosis and Lung
Disease Research Institute*

Francesco Bonella

Ruhrlandklinik University Hospital

Marlies Wijsenbeek *Centre of
Interstitial Lung Diseases, Erasmus
MC, University Medical Centre,
Rotterdam, The Netherlands*

Michael Kreuter

University of Heidelberg

Arzu Yorgancıoğlu

*Celal Bayar University Medical
Faculty*

Lesley Ann Saketkoo

*New Orleans Scleroderma and
Sarcoidosis Patient Care and
Research Center and Person-
Centred Care*

Gisli Jenkins

Imperial College London



Pharmaceutical Representatives

Paul Ford
Galapagos

Josep Fortea Busquets
*Boehringer Ingelheim
International GmbH*

Others

Pippa Powell
European Lung Foundation

Laura Fregonese
European Medicine Agency

Anita K. Simonds
European Respiratory Society



Summit Sessions

Speakers · Content · Key Quotes and Insights · Metrics and Analytics



Summit Agenda

Day 1 – 23rd April 2021		
13:00h - 14:00h	Opening Session	
14:30h - 15:30h	Mechanism of action of fibrosis and new insights on antifibrotic drugs	Research
16:00h - 17:00h	Self-management of ILD	Person-Centered Care
17:30h - 18:30h	Supporting newly diagnosed patients	Advocacy
19:00h – 20:00h	Breaking barriers: How to optimize communication between physicians, patients and loved ones	Industry Symposium
Day 2 – 24th April 2021		
09:30h – 10:30h	Industry Symposium: Improving the path to diagnosis in Europe: the doctor, patient and caregiver’s perspective	Industry Symposium
11:00h - 12:00h	Non-pharmacological management of IPF/ILD and evaluation for lung transplant	Person-Centered Care
12:30h - 13:30h	Involvement of rare disease patient representatives in medical congresses	Advocacy
16:00h - 17:00h	Clinical trials for IPF & ILD and an overview of potential therapies moving forward	Research
16:00h - 17:00h	Role of interdisciplinary team in hospice and end of life	Person-Centered Care
17:30h -18:30h	Multidisciplinary and/or interdisciplinary approaches to ILD care	Person-Centered Care
Day 3 – 25th April 2021		
11:00h - 12:00h	Pulmonary rehabilitation for IPF patients	Person-Centered Care
12:30h - 13:30h	What patients want to know about research and how they can be involved?	Research
16:00h - 17:00h	The 2030 EU Agenda on rare diseases	Advocacy
16:00h - 17:00h	Closing Session	



I. PF Patient Summit Opening Session

Content of the Round Table

In the opening session Steve Jones, President of the EU-IPFF, gave a statement on the achievements of the federation, its mission and challenges that lie ahead. Anita Simonds highlighted projects and initiatives of the European Respiratory Society, the process of transitioning to a post-acute Covid era and the role of technology in treating lung diseases. Wim Wuyts spoke about the history of the EU-IPFF, its achievements at EU level as well as improvements in awareness and expertise. Lastly, Ron and Maxine Flewett provided a perspective on the impact of IPF on patients and carers.

Key Quotes and Insights

- “Our job is to campaign for more funding for more research on IPF and to ensure that patients are involved in it. We need to rethink the way how clinical trials are organized and make patients aware of the benefits of taking part in trials.” *(Steve Jones)*
- “There is a high need for understanding the disease and to invest in genetic research.” *(Wim Wuyts)*
- “A nurse told me: your life will become like a roller coaster, hills will become your enemy.” *(Ron Flewett)*
- “I had panic attacks, I couldn’t do my job as well and it also had a financial impact. I’ve had issues with my mental well-being from diagnosis to the present day.” *(Ron Flewett)*
- “We have to take on more responsibilities: I now mow the lawn, I do the heavy lifting. Everything we do requires planning and making sure it’s worth doing.” *(Maxine Flewett)*
- “Both our worlds get smaller as the disease progresses: our friends seem to back away. They don’t know how to deal with the disease. Our social life is shrinking. How often are we as carers – loved ones – asked how we are?” *(Maxine Flewett)*

Speakers



Steve Jones (Moderator)

EU-IPFF and Chair



Anita K. Simonds

European Respiratory Society



Wim Wuyts

University Hospital Leuven



Maxine Flewett

Caregiver



Ron Flewett

Pulmonary Fibrosis Trust Trustee



II. Mechanism of action of fibrosis and new insights on antifibrotic drugs

Content of the Presentation

In this session, moderated by Anna-Maria Hoffmann-Vold, Helen Parfrey gave an overview of the main profibrotic pathways, genetic factors implicated in lung fibrosis development and progression and how genetics improve the understanding of disease mechanisms. Francesco Bonella focused on how current antifibrotic drugs such as Pirfenidone and Nintedanib inhibit disease progression and affect life expectancy and how there are still unmet needs regarding Quality of Life and side effects, and Howard Almond provided a patient perspective on current antifibrotic treatment options and how to involve patients in treatment decisions, ending with a call for more research and the collection of detailed patient data.

Key Quotes and Insights

- “Lung function is the best biomarker right now, but there might be more effective biomarkers, e.g. from a blood test, that may guide us to a change in treatment.” *(Helen Parfrey)*
- “The genes we know only account for 30 % of the causes of familial PF. Smoking for example can actually modify our DNA in a process called epigenetic modification.” *(Helen Parfrey)*
- “Genetics may help in identifying people who are more susceptible to get a progressive disease and in personalising treatments für PF.” *(Helen Parfrey)*
- “In the next 5 years we will see a dramatic change in how we treat patients with PF.” *(Helen Parfrey)*
- “If you look at the biopsy of a patient with PF you often see a thickening of the blood vessels. We have never understood whether this is a consequence or a cause of fibrosis.” *(Helen Parfrey)*
- “Compared to 10, 15 years ago, today we have data on the combination of drugs from ongoing clinical trials. Now we have the add-on strategy in clinical trials.” *(Francesco Bonella)*
- “The first thing that I advise people to do is contact a specialist.” *(Howard Almond)*

Speakers



Anna-Maria Hoffmann-Vold (Moderator)
Oslo University Hospital



Howard Almond
Action Pulmonary Fibrosis UK



Helen Parfrey
Royal Papworth Hospital



Francesco Bonella
Ruhrlandklinik University Hospital



III. Self-management of ILD

Content of the Presentation

In this presentation, David Crosby, a double lung transplant recipient and member of the Irish Lung Fibrosis Association, gave an insight into how the disease has shaped his life, how it took his three siblings and how patients can have a positive impact on their own well-being by setting and accomplishing goals. Anne-Marie Russell elaborated on the importance of self-care and how patients can improve it by using home devices and smartphone apps, but also through breathing exercises such as singing. Lesley Ann Saketkoo described how symptom distress can affect quality of life, how interventions on symptom distress can improve survival, treatment tolerability and feasibility and presented mindfulness as a strategy towards improved self-management. Viewers were encouraged to take part in a live mindfulness exercise.

Key Quotes and Insights

- “Yoga has helped me immensely through my journey.” *(Ron Flewett)*
- “Everybody has blue days, it’s like a mist. What I do: I go for a walk to clear that mist and get the blood to circulate in the body.” *(David Crosby)*
- “We have to become our own best advocates in navigating the systems.” *(Anne-Marie Russell)*
- “Water is one of the most enhancing environments for exercising. The water creates a type of resistance, but also a support. You will get more of a challenge for the muscles. But it can be easy to overdo it in the water– you need to listen to yourself.” *(Lesley Ann Saketkoo)*

Speakers



Ron Flewett
Pulmonary Fibrosis Trust Trustee



David Crosby
Irish Lung Fibrosis Association



Anne-Marie Russell
EU-IPFF Scientific Advisory Board



Lesley Ann Saketkoo
New Orleans Scleroderma and Sarcoidosis Patient Care and Research Center and Person-Centred Care



IV. Supporting newly diagnosed patients

Content of the Presentation:

This session explored the experiences of patients around diagnosis and gave them the opportunity to discuss and address unmet needs. Additionally, it focused on the importance of specialist nurses for both patients and physicians, the nurse/patient relationship, the role of patient organisations in the diagnosis experience, and highlighted challenges during diagnosis and beyond faced by patients and nurses face on a daily basis.

Key Quotes and Insights

- “I still get very emotional thinking about these 30 minutes when I got the diagnosis. The shock is brutal. You are alone with a new friend – a bad friend: google search.” *(Jean-Michel Fourier)*
- “I tell patients to make sure the information is from an informed platform.” *(Paula Ryan)*
- “I learned to take care of myself and others. This is some kind of opportunity, too.” *(Jean-Michel Fourier)*
- “First of all, patients and families need better support and psychological support when they get diagnosed and we need to refer them to patient organisations and support groups. Second of all, there is a lack of knowledge about rare diseases – we need to train our doctors, general practitioners and pneumologists better. Thirdly, we need more specialist nurses because they can improve patients’ quality of life immensely. And finally, pneumologists need to have more confidence in patient support groups. This is a must for our quality of life. Don’t let them leave your office without a contact to a patient organization.” *(Jean-Michel Fourier)*
- “ILD nurses are one of the most important pillars of support in the beginning as well as throughout the course of the disease – for patients but also for physicians. In my experience patients are more open with an ILD nurse than with physicians. It’s very difficult for patients to understand and accept that there is no known cause for the disease.” *(Julia Wälscher)*

Speakers



Louise Wright
(Moderator)
Action for Pulmonary Fibrosis



Julia Wälscher
Ruhrlandklinik University Hospital



Paula Ryan
UL Hospitals, Limerick



Jean-Michel Fourier
EU-IPFF Secretary,
President of APEFPI



V. Breaking barriers: How to optimize communication between physicians, patients and loved ones

Content of the Symposium:

This symposium explored the challenges associated with doctor-patient communication around the diagnosis of pulmonary fibrosis, the relevance of doctor-patient, doctor-doctor and patient-patient communication as well as how communication models such as SPIKES, a model for delivering bad news, can help physicians, patients and loved ones to optimize solutions to this issue. Furthermore, the speakers pointed out ways to encourage transparent and empathetic communication by physicians, and shared practical tips for patients like preparing for a meeting, bringing someone who can take notes, sharing one's medical history or how loved ones can offer support at the doctor's office.

Key Quotes and Insights

- “I didn't understand the implication of what it meant.” *(Ron Flewett)*
- “When you've been told a lot of information you might not understand all of it at that time. Most people are too worried to say: wait a minute, I don't understand.” *(Maxine Flewett)*
- “For physicians communication is a core competency. Patients' feedback has driven this: doctors asked patients to rate them based on their communication skills.” *(Walter Baile)*
- “Patient organisations have a massive role to play, especially for people who are a bit quiet at the doctor's office.” *(Maxine Flewett)*
- “It's about being confident that no matter how silly your questions might be, your clinician will respect that you made the effort to find out.” *(Maxine Flewett)*
- “Sometimes patients are afraid to ask about mental health problems. A phrase that is useful to ask patients is: how are you handling things? What we teach doctors is: stay quiet and give patients space, let them emote.” *(Walter Baile)*

Speakers



**Josep Fortea Busquets
(Moderator)**

Boehringer Ingelheim
International GmbH



Maxine Flewett

Caregiver



Ron Flewett

Pulmonary Fibrosis Trust Trustee



Claudia Valenzuela

Hospital Universitario de
la Princesa



Walter Baile

University of Texas
MD Anderson





VI. Improving the path to diagnosis in Europe: the doctor, patient and caregiver's perspective

Content of the Symposium

In this session Steve Jones presented the results of the EU-IPFF/Galapagos patient journey survey in Europe before these findings were discussed from the different perspectives of a doctor, patient and caregiver. The symposium highlighted some of the challenges IPF poses to this day, such as delayed diagnosis, the timely referral to a respiratory clinic for testing, the importance of CT scans and the role of patient organisations and support groups.

Key Quotes and Insights

- “I went to the doctor with a persistent dry cough. That was two years before I experienced a shortness of breath. The key step is to get your general practitioner to refer you to a respiratory clinic.” (Steve Jones)
- “We need a lot more specialist nurses for ILD.” (Steve Jones)
- “You can't think straight when you're diagnosed. That's the time when a fellow patient further down the track can help you and show you how life with IPF can be.” (Steve Jones)
- “We need community-based facilities that can provide CT scans.” (Steve Jones)
- “There are so many things that could be done earlier.” (Chantal Vandendungen)
- “There are two main topics: the training for general practitioners and the importance of support groups. People often suffer from IPF for years and never get a CT scan.” (Jean-Michel Fourrier)
- “Support groups are important for families and carers, too – not just for patients.” (Jean-Michel Fourrier)
- “Patients already lose a lot of lung function during the process of diagnosis. We need education on all levels. Awareness campaigns play an important role in getting patients to see a general practitioner and avoid a delayed diagnosis.” (Marlies Wijsenbeek)

Speakers



Steve Jones (Moderator)

EU-IPFF and Chair



Marlies Wijsenbeek

Centre of Interstitial Lung Diseases, Erasmus MC, University Medical Centre, Rotterdam



Jean-Michel Fourrier

EU-IPFF Secretary,
President of APEFPI



Chantal Vandendungen

ABFPI Vice President for
International Relations



VII. The psychological aspects of living with chronic disease

Content of the Presentation

This session gave an overview of the psychological impact of rare chronic diseases from the perspective of clinicians, caregivers and patients. Patients and caregivers affected by various kinds of rare diseases shared their experiences and coping mechanisms and how the disease not only has an impact on themselves but also on their relationships and loved ones and their daily lives.

Key Quotes and Insights

- “My daughter convinced me that functioning is not living. A chronic disease is an adjustment of life – not the end of it. There will have to be adjustments along that pathway.” *(Liam Galvin)*
- “In the subconscious of all lung patients the most important topic is surely death.” *(Stefano Pavanello)*
- “You’re not autonomous anymore, in fact you’re totally dependent. Your body changes a lot, too. Sometimes it is difficult to find the will to fight for yourself.” *(Stefano Pavanello)*
- “I have experienced dramatic stories with other patients, but also beautiful stories.” *(Stefano Pavanello)*
- “We tried to simplify our life, we had to adapt our physical activities, we had to adjust the house. My whole life started to revolve around care, there was no other way in my case.” *(Chantal Vandendungen)*
- “Both patients and caregivers are survivors. There is joy in small things, don’t give up on life.” *(Chantal Vandendungen)*
- “Make sure that you as a patient are also taking care of your partner, just as your partner is taking care of you. I look at the things I can do, not at the things I can’t do.” *(Joep Welling)*
- “Depression and anxiety have an impact on patients’ quality of life. The disease has an impact on their loved ones, too.” *(Elisabetta Balestro)*

Speakers



Liam Galvin (Moderator)
CEO Secretariat EU-IPFF



Elisabetta Balestro
University Hospital of Padova



Stefano Pavanello
Unione Trapiantati Polmone –
Padova Representative



Chantal Vandendungen
ABFPI Vice President for
International Relations



Joep Welling
NVLE - Dutch P.O. for Lupus,
Scleroderma



VIII. Involvement of rare disease patient representatives in medical congresses

Content of the Round Table

In this round table session Klaus Geißler elaborated on patient involvement in medical congresses as well as the role of patient advocates in their respective patient organisations and shared his experience as an IPF advocate at scientific meetings. Michael Kreuter shared how clinicians and researchers benefit from the participation of patient advocates in scientific congresses and the importance of a holistic approach to patient-centered care. Jan Geißler explained how the legal framework hinders the participation of patients at medical congresses, and Pippa Powell described how ESMO, ECCO and EHA have overcome these issues so that patient advocates can attend and participate in medical congresses.

Key Quotes and Insights

- “Klaus actually changed the wording for the German treatment guidelines for IPF.” *(Michael Kreuter)*
- “We need to continue meetings like today and we need physicians to explain what new information means in the context of a disease.” *(Michael Kreuter)*
- “I like to attend congresses to learn and to use this knowledge later on in conversations with my doctor or other patients. We need to support communication, it’s our most important tool.” *(Klaus Geißler)*
- “It’s key for patient advocates to attend scientific conferences: to see how researchers push the boundaries, and to challenge clinicians with the patient’s perspective.” *(Jan Geißler)*
- “It’s professionals working with patients who say: wow, that added to my experience!” *(Pippa Powell)*
- “Get involved, any of you at any level. Join EU-IPFF, come to the local organisations, do the EUPATI courses, join the patient ambassador program, join a patient advocacy group. Get involved.” *(Pippa Powell)*

Speakers



Jan Geißler (Moderator)
Patvocates



Klaus Geißler
EU-IPFF



Michael Kreuter
University of Heidelberg



Pippa Powell
European Lung Foundation



IX. Clinical trials for IPF & ILD and an overview of potential therapies moving forward

Content of the Presentation

In this presentation Toby Maher presented an overview of clinical trials and explained how they are designed and implemented and how patients and other stakeholders are involved. Following this, Vincent Cottin gave an insight into currently available treatment options, the combination of novel and available drugs, ongoing phase 3 trials for Pamrevlumab and Pentraxin-2 as well as early-stage phase 1 and 2 trials and other novel treatment targets like G protein-coupled receptors, before Steve Jones shared a patient's perspective on what needs to be achieved to improve access to clinical trials and how this has been affected by Covid-19.

Key Quotes and Insights

- “If we want to expand the number of patients, we need to expand the number of trial sites or make it easier for patients to get to these trial sites.” *(Steve Jones)*
- “New trials will add on existing therapies rather than trying to replace them. It is not ethical to deny patients access to treatment.” *(Toby Maher)*
- “All trials have rules – inclusion and exclusion criteria – about what patients can participate. In some trials these rules are very strict which makes it difficult for patients to join.” *(Toby Maher)*
- “A trial is an opportunity to get access to a new drug early – sometimes years earlier.” *(Vincent Cottin)*
- “We have seen that we're moving towards designed trials which are more inclusive of patients with any form of PF. That change will make it easier for patients to participate in clinical trials. I agree that it is very frustrating for patients not to be able to participate when they are keen to do so.” *(Toby Maher)*
- “Reversing PF should be our goal. But it's not just about finding better treatments, it's about finding ways to identify patients with PF earlier before there is a lot scar tissue and fibrosis.” *(Toby Maher)*
- “I'll be optimistic and say that it will be possible to reverse PF in the future.” *(Vincent Cottin)*

Speakers



Paolo Spagnolo
(Moderator)
University of Padua



Toby Maher
Keck School of Medicine



Vincent Cottin
Louis Pradel University Hospital
and Claude Bernard University



Steve Jones
EU-IPFF and Chair



X. The importance of palliative care

Content of the Presentation

The objective of the session was to give a definition of palliative care, its role in moderate to end stage pulmonary fibrosis, to share how professionals can have a positive impact on symptom management, quality of life, dignity and communication with patients and their loved ones, and to explain the impact of planning palliative care for patients and their loved ones.

Key Quotes and Insights

- “Palliative care also provides end of life care, but it is not only end of life care.” (*Gudrun Kreye*)
- “End of life care is very important. Palliative care should start earlier when there is no chance of cure – it can last years.” (*Gudrun Kreye*)
- “Contrary to popular belief, palliative care should be offered to patients as soon as needed – in the very beginning of the disease depending on the patient’s needs.” (*Ewa Jassem*)
- “Palliative care is a form of care that provides a relief of disease symptoms. According to the WHO, it’s appropriate at any stage of a disease.” (*Gudrun Kreye*)
- “Fear is a barrier. In my experience patients with lung diseases are more reluctant to accept palliative care than cancer patients, for example. We need to convince patients that palliative care is not only end of life care.” (*Gudrun Kreye*)
- “We now have the treatment options to alleviate pain and suffering.” (*Ewa Jassem*)

Speakers



**Guenther Wanke
(Moderator)**

Lungenfibrose Forum Austria



Ewa Jassem

University Hospital in Gdańsk,
Poland



Gudrun Kreye

Palliative Care Unit in Krems



Sabin Handzhiev

Universitätsklinikum Krems



XI. Multidisciplinary and/or interdisciplinary approaches to ILD care

Content of the Presentation

In this session Alexander Simidshiev shared his experience of being part of a multidisciplinary team, the necessity of a specialist approach and how a team approach benefits his work and patients, whereas Kathleen Leceuvre described the role of specialist nurses in interstitial lung disease and their respective tasks in a holistic approach. Simon Walsh talked about when an MDT is needed from the perspective of a radiologist, the challenges in ILD diagnosis and its contribution to the MDT, and Anna Murphy described the role of respiratory pharmacists in the ILD MDT and how they benefit healthcare providers and patients.

Key Quotes and Insights

- “The MDT has a training effect on clinicians and improves their diagnostic accuracy.” (*Simon Walsh*)
- “Multidisciplinary means that you have different disciplines, but each participant is focusing on their own discipline, whereas interdisciplinary describes the process where all of these disciplines are integrated into one approach. So the result is interdisciplinary, but the process is multidisciplinary.” (*Simon Walsh*)
- “In an MDT people from different disciplines have their own voice and use their own experience to try to improve the care for patients. Interdisciplinary describes networking and bringing this knowledge together.” (*Anna Murphy*)

Speakers



Radostina Getova
(Moderator)
EU-IPFF



Alexander Simidchiev
Association Air For Health



Katleen Leceuvre
UZ Leuven



Simon Walsh
National Heart and Lung
Institute Imperial College



XII. Pulmonary rehabilitation for PF Patients

Content of the Presentation

This presentation held by Jean-Michel Fourrier, Sally Singh and Irene Byrne revolved around the importance of pulmonary rehabilitation for patients with pulmonary fibrosis and how it has developed, and provided practical examples such as online courses specifically developed for patients with IPF for keeping fit during the Covid-19 pandemic, e.g. “IPF & Me” by Siel Blue or “Mooven” by the patient organisation APEFPI.

Key Quotes and Insights

- “Often carers or relatives get sidelined and they also need support. We mustn’t forget family in that as well.” *(Sally Singh)*
- “One of the challenges is recreating peer support with digital platforms in a way that you get with a face-to-face contact.” *(Sally Singh)*
- “Patients bring their own remedies for simple things like cough. Medics can’t cover all of the points. There’s nothing that can match face-to-face peer support which is hugely important.” *(Irene Byrne)*
- “We need to sell the importance of exercising, which is difficult to maintain when your mental health is in decline.” *(Irene Byrne)*
- “Patient organisations can help by lobbying hospitals, clinicians and professionals to realise that exercising is important and access to physiotherapy is essential. And by helping patients maintain their healthy lifestyle.” *(Irene Byrne)*
- “The problem with a progressive disease is that when there’s a progression, patients are tempted to give up and think that all the work/exercise didn’t help.” *(Irene Byrne)*

Speakers



Jean-Michel Fourrier
(Moderator)

EU-IPFF Secretary,
President of APEFPI



Sally Singh

University Hospitals of Leicester
NHS Trust



Irene Byrne

University Hospital Dublin



XIII. What patients want to know about research and how they can be involved

Content of the Panel Discussion

The main topics of this panel discussion were patient and public involvement in clinical trials, existing barriers and requirements that have to be met both from a patient and research perspective, the importance of patient reported outcomes and the need for new endpoints for clinical trials in IPF.

Key Quotes and Insights

- “For IPF we have only one endpoint: forced vital capacity. If you’re stable, your forced vital capacity may not be changing very quickly – which makes it difficult to tell if a drug is working. And there are many faults to FVC which is why we need a different endpoint.” *(Paul Ford)*
- “There are a lot of initiatives by the EMA to involve patients at every stage of development and study design. I think there is some flexibility in looking at patient reported outcomes as secondary endpoints. We need scientists to be able to link these secondary endpoints to the disease.” *(Laura Fregonese)*
- “Patient organisations can help educating patients about ongoing clinical trials.” *(Raymond Blessing)*
- “We have to learn how to look at data together: what are meaningful data? How can we make conclusions that are relevant to patients, how can we put those in a relevant clinical context and how can we formulate them so that everybody understands their relevance? We have to educate patients in how to give meaningful input in these trials and be skilled advisors.” *(Marlies Wijsenbeek)*
- “We have to balance our study design: quality of data versus comfort of the patients. It is crucial to make patients feel important and necessary for the strategy of developing a drug. We need big awareness campaigns, because there is a lot of bad publicity about clinical trials. But without them there is no progress in the development of treatments.” *(Katarzyna Lewandowska)*

Speakers



**Michael Kreuter
(Moderator)**
University of Heidelberg



Marlies Wijsenbeek
Centre of Interstitial Lung
Diseases, Erasmus MC, University
Medical Centre, Rotterdam



Raymond Blessing
The Netherlands Pulmonary Fibrosis
Patients Association



Paul Ford
Galapagos



Laura Fregonese
EMA



Katarzyna Lewandowska
National Tuberculosis and Lung
Disease Research Institute



XIV. The 2030 EU Agenda on rare diseases

Content of the Round Table

This round table session examined the status of new and ongoing EU policies that impact pulmonary fibrosis patients and provided case studies on initiatives funded by the European Union of which the EU-IPFF are members. It also explored strategic partnership opportunities that can improve the EU's policies on rare diseases.

Key Quotes and Insights

- “We need to strive for disease prevention.” (*Arzu Yorgancioğlu*)
- “It is very important that patients and clinicians work together. The EU has a tradition of supporting research in rare diseases.” (*Liam Galvin*)
- “If the prevalence is below 5 per 10,000 we are talking about a rare disease. All data suggest that IPF is on the rise, but it is still a rare disease – a frequent rare disease, I would say.” (*Andreas Günther*)
- “Being able to provide an effective treatment changes people’s awareness a lot.” (*Andreas Günther*)
- “I believe that we should use Covid to promote the importance of respiratory diseases. This time people are aware that these diseases exist. We should use it as a tool.” (*Arzu Yorgancioğlu*)
- “Sadly, there are a number of patients who develop fibrosis as a long-term response to Covid-19. This confirms that epithelium injury is the driving force for fibrosis.” (*Andreas Günther*)
- “We will have post-Covid patients dealing with fibrosis.” (*Arzu Yorgancioğlu*)

Speakers



Liam Galvin (Moderator)
CEO Secretariat EU-IPFF



Andreas Guenther
University Gießen



Gergely Meszaros
PHA Europe



Arzu Yorgancioğlu
Celal Bayar University Medical
Faculty



XV. PF Patient Summit Closing Session

Content of the Closing Session

In this session Carlos Lines, founding member and former president of EU-IPFF, gave an overview of the federation's history, its aims and achievements as well as a summary of EU and national policies that will shape the future of patients with pulmonary fibrosis. Gisli Jenkins talked about Covid-19 and its implications for patients with PF, the joint challenges of Covid-19 and curing pulmonary fibrosis as well as the progress made in fighting the disease and hopes for the future. Steve Jones in the closing address said that EU-IPFF is looking forward eagerly to the 2nd European Pulmonary Fibrosis Patient Summit in 2023!

Key Quotes and Insights

- “In a couple of years, we should be using biomarkers routinely. If we can develop a biomarker that changes over a month, this will lead to much shorter clinical trials. We would have to clearly associate the change in biomarker with a hard outcome such as mortality.” *(Gisli Jenkins)*
- “There are data that suggest that we might be able to shorten clinical trials to 3 months.” *(Gisli Jenkins)*
- “The data that we sight are from the point of diagnosis – they don't include the time before diagnosis. If you diagnose from the first symptom, your median survival will be around 6 years, and if you add antifibrotics it might be around 8 years. But we want to be well into double figures – which means that we want to diagnose earlier, and then stop the fibrosis from progressing.” *(Gisli Jenkins)*
- “The genetic risk for IPF is higher than just about any other complex disease. We don't know the majority of the relevant genes, but we know a lot of them.” *(Gisli Jenkins)*
- “Covid-19 may lead to pulmonary fibrosis, although we think that for the vast majority this will not be a problem. Understanding post Covid fibrosis may provide the opportunity to develop strategies to remodel fibrotic lung.” *(Gisli Jenkins)*

Speakers



Steve Jones (Moderator)

EU-IPFF and Chair



Carlos Lines

EU-IPFF President Emeritus



Gisli Jenkins

Imperial College London

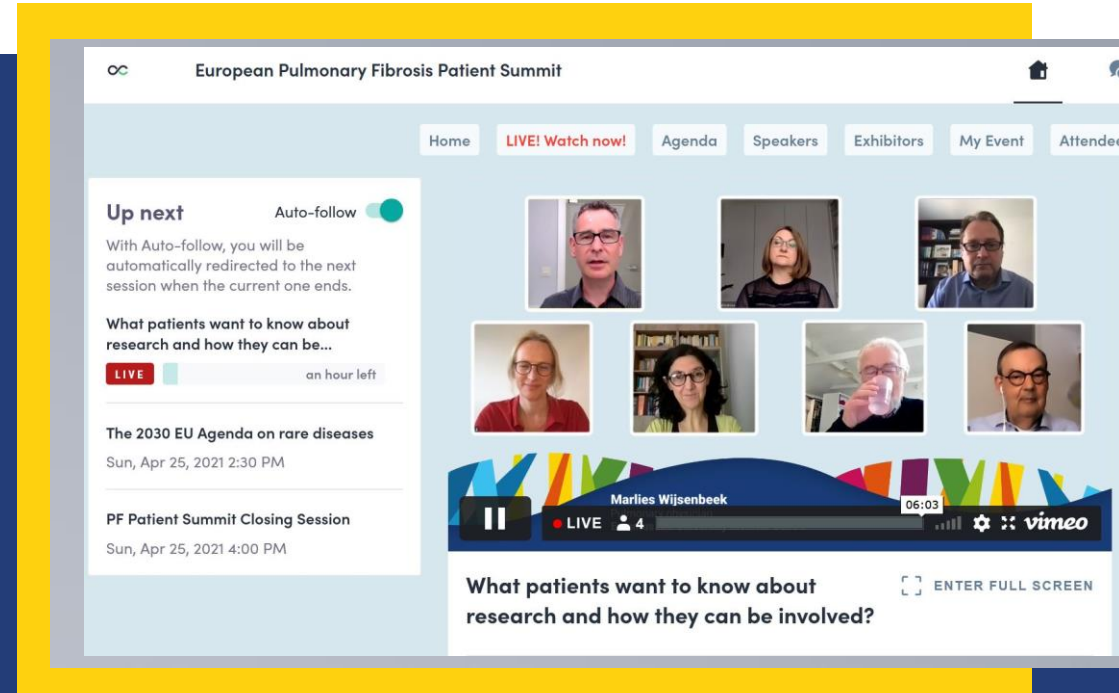


Sessions – Metrics Analysis

All sessions of the PF Summit were streamed live via the Summit Platform in Swapcard.

During the sessions, the attendees were able to send questions and comments in the live discussion panel.

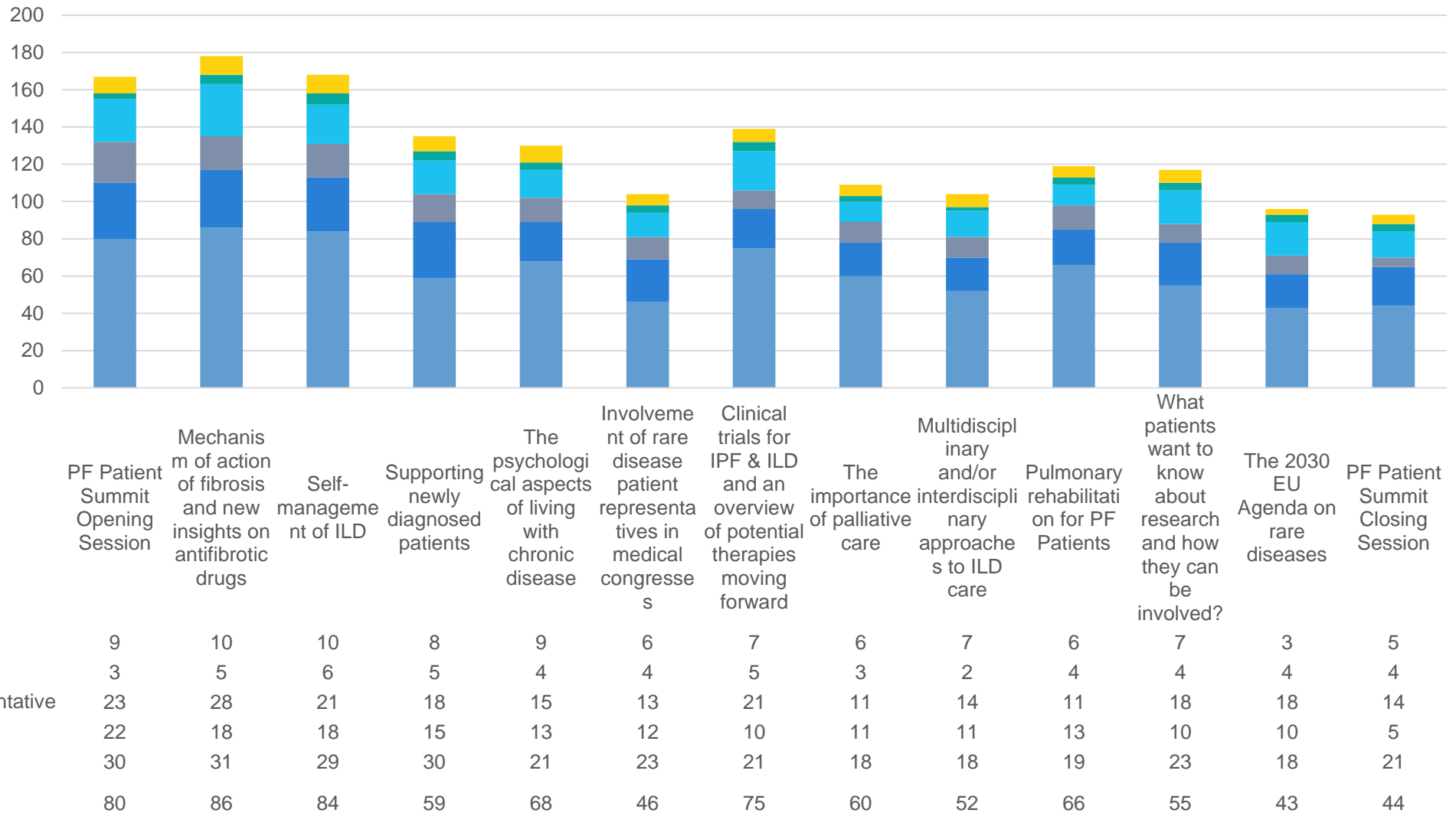
Over the three-day Summit, 13 official sessions and 2 industry symposiums were held. The average number of viewers connected to the live stream was **126**. The session with the highest number of live views was *Mechanism of action of fibrosis and new insights on antifibrotic drugs (179)*.



The screenshot displays the live stream interface for the European Pulmonary Fibrosis Patient Summit. The top navigation bar includes links for Home, LIVE! Watch now!, Agenda, Speakers, Exhibitors, My Event, and Attendee. The main content area features an 'Up next' section with an 'Auto-follow' toggle, a list of upcoming sessions including 'What patients want to know about research and how they can be...' (LIVE, an hour left), 'The 2030 EU Agenda on rare diseases' (Sun, Apr 25, 2021 2:30 PM), and 'PF Patient Summit Closing Session' (Sun, Apr 25, 2021 4:00 PM). A grid of speaker video thumbnails is visible. The bottom of the interface shows a video player for the current session, 'What patients want to know about research and how they can be involved?', with a 'LIVE' indicator, 4 viewers, and a 'vimeo' logo. The speaker's name, Marlies Wijsenbeek, and the time 06:03 are also displayed.



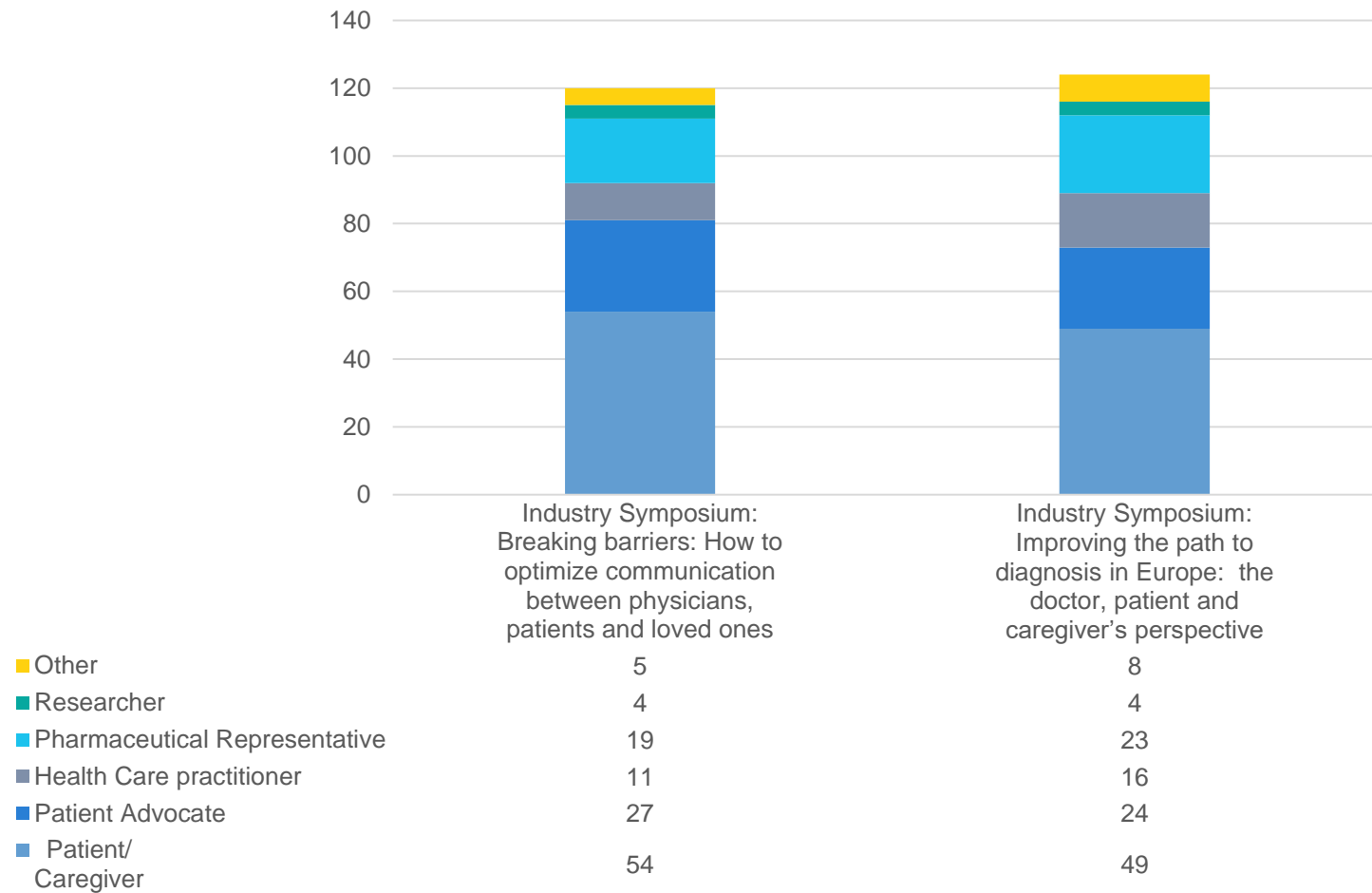
STAKEHOLDER DISTRIBUTION OF THE PF SUMMIT LIVE VIEWERS



These graphs show the number of live viewers for each official session of the PF Summit. Furthermore, you can see the distribution of the viewers based on the type of stakeholder.



STAKEHOLDER DISTRIBUTION OF THE PF SUMMIT INDUSTRY SYMPOSIUM LIVE VIEWERS



These graphs show the number of live viewers for each official session of the industry symposium at the PF Summit. Furthermore, you can see the distribution of the viewers based on the type of stakeholder.



Posters & Abstracts



Posters and Abstracts

Person-Centered Care

- Improving The Quality Of Life With Dietotherapy (*Klaudia Vincze*)
- Interim Analysis Of Patient Satisfaction With The Digital Ecosystem Used In The STARLINER Study Of Disease Behaviour In Interstitial Lung Disease (*Marlies S. Wijsenbeek et al.*)
- Interim Analysis Of Patients With Interstitial Lung Disease Enrolled In The STARLINER Study (*Marlies S. Wijsenbeek et al.*)
- Patient reported experiences and delays during the diagnostic pathway for pulmonary fibrosis: results from a multinational survey (*I.G. van der Sar et al.*)
- Home Spirometry as an Endpoint in Interstitial Lung Disease Clinical Trials – Lessons Learned (*Toby M. Maher et al.*)

Policy and Patient Advocacy

- Study design of an international patient-led registry in fibrotic interstitial lung diseases using eHealth technology: I-FILE (*drs. G. Nakshbandi, drs. C.C. Moor, dr. M.S. Wijsenbeek*)
- The “IPF & Me” program (*Guillame Lefebvre and Fleur-Amelie Fayard*)
- The Trials and Tribulations of Forming a Support Group (*John Conway, Dr Dimitra Nikoletou*)
- Voice of the Patient Social Media Analysis: Idiopathic Pulmonary Fibrosis disease awareness and Patient Journey (*Carmela Pratelli et al.*)
- Do you know the Netherlands’ Pulmonary Fibrosis Patient Association? (*Raymond Blessing*)

Research

- Investigating The Effects Of Stimulating The Angiotensin II Type 2 Receptor On Lung Function In Patients With IPF (*Rohit Batta, Joanna Porter, Göran Tornling, Johan Raud*)
- Bleomycin and Collagens: A Focus on The Rat Model of Lung Fibrosis (*Chiesi*)
- Time-course analysis of multiple readouts in the bleomycin-induced pulmonary fibrosis mouse model (*Chiesi*)
- Artificial intelligence-based histological scoring of lung fibrosis in rodent models of lung fibrosis (*Chiesi*)



Exhibitor's Space

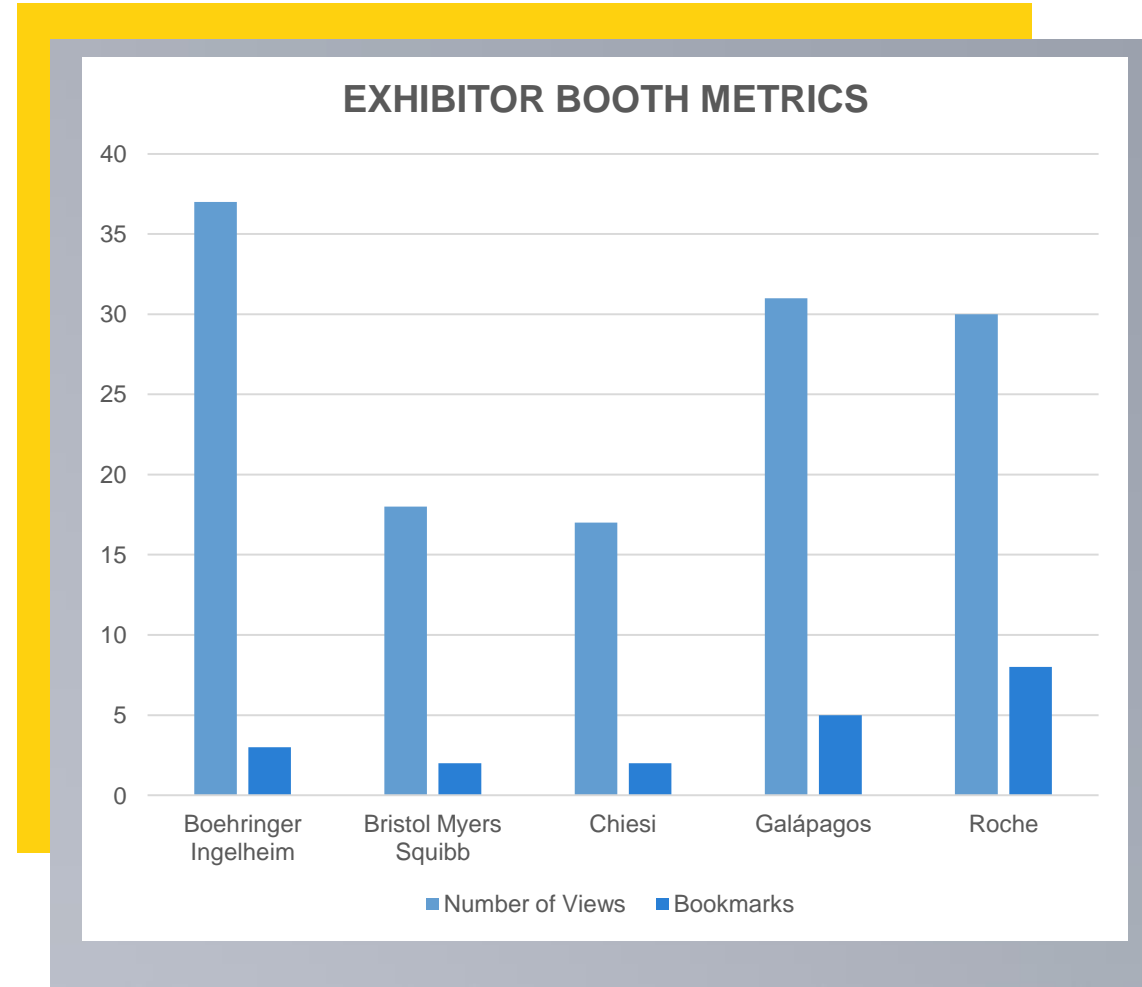


Exhibitor's Space Metrics

There was 5 exhibitor Spaces at the PF Summit Platform



The graph shows how many individual users viewed a particular exhibitor booth and how many times it was bookmarked.

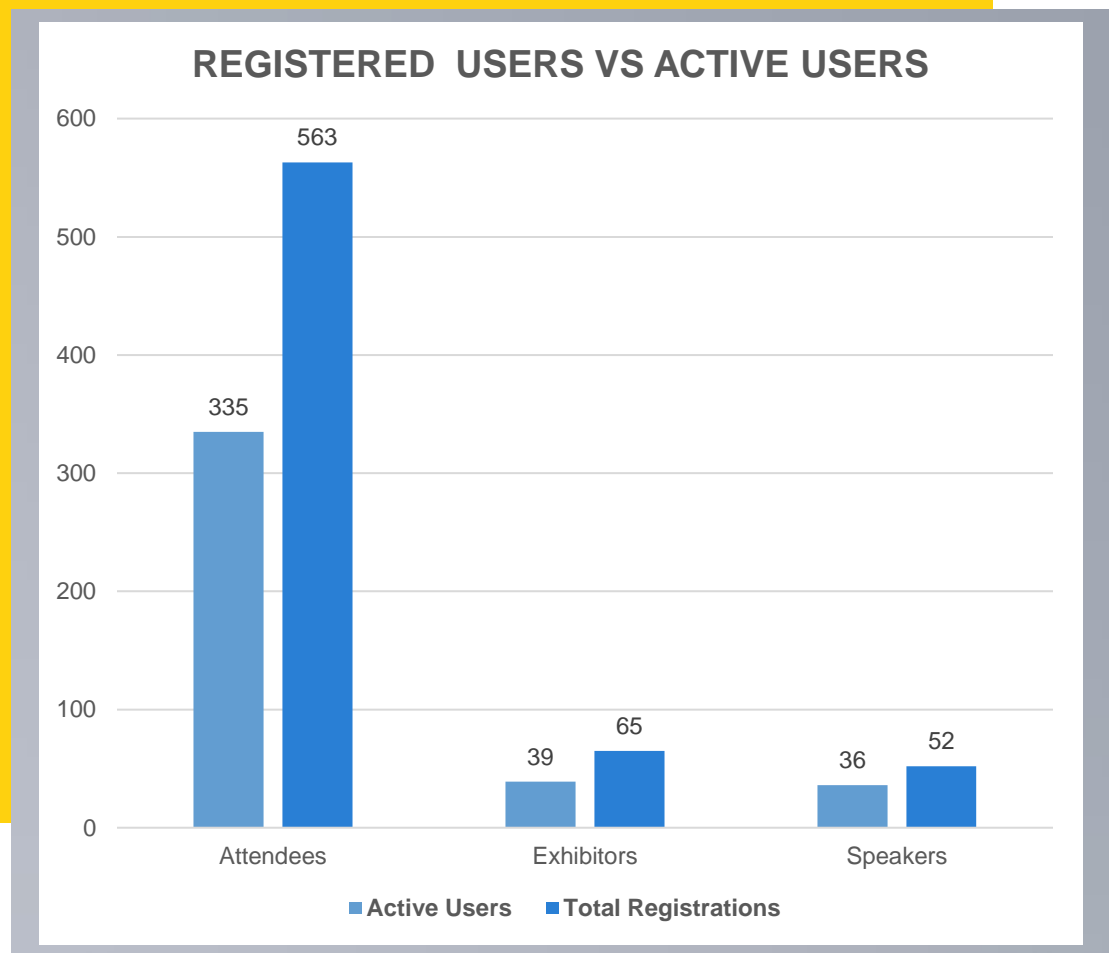


Review and metrics of the PF Summit Attendance

Registered vs. Active Users by Type of User and Country



Attendee Participation - Overview



The registrations for the PF Summit were opened on 1st of February until the 20th of April. During this time, 685 people registered for the event (including speakers, exhibitors and organisations).

Of the registered attendees, 335 actively participated in the Summit via the online platform (59.5%).

As per the survey sent to the users that did not activate their profile, 50% confirmed that they could not attend the Summit due to changes in their personal plans. 20% confirmed as well that they were not able to log into the Summit platform or could not find the instructions on how to do it

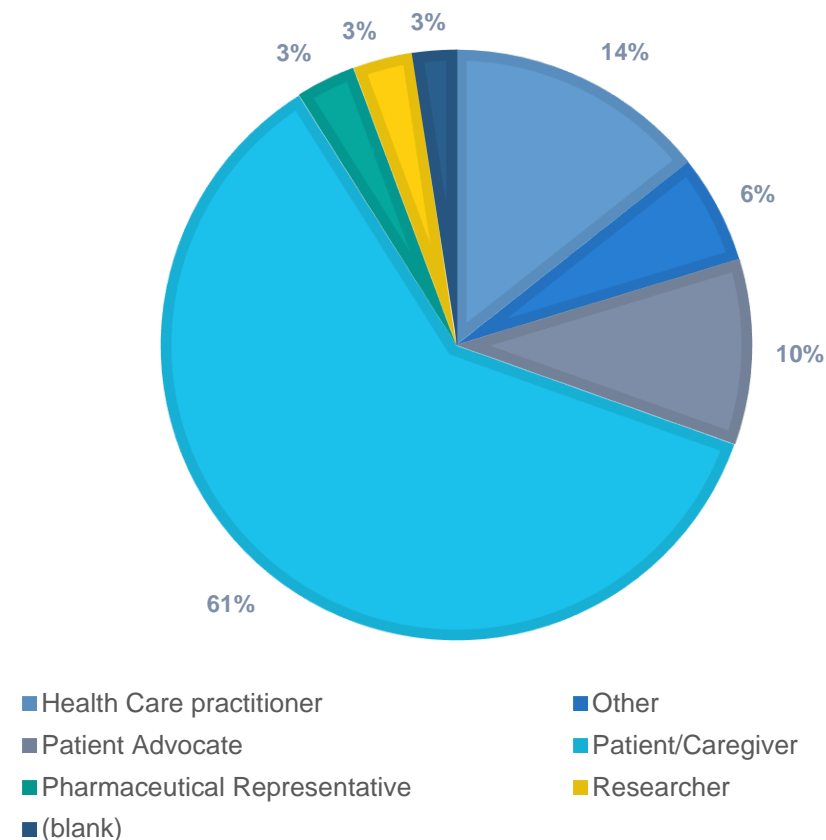


Attendee Participation - Overview

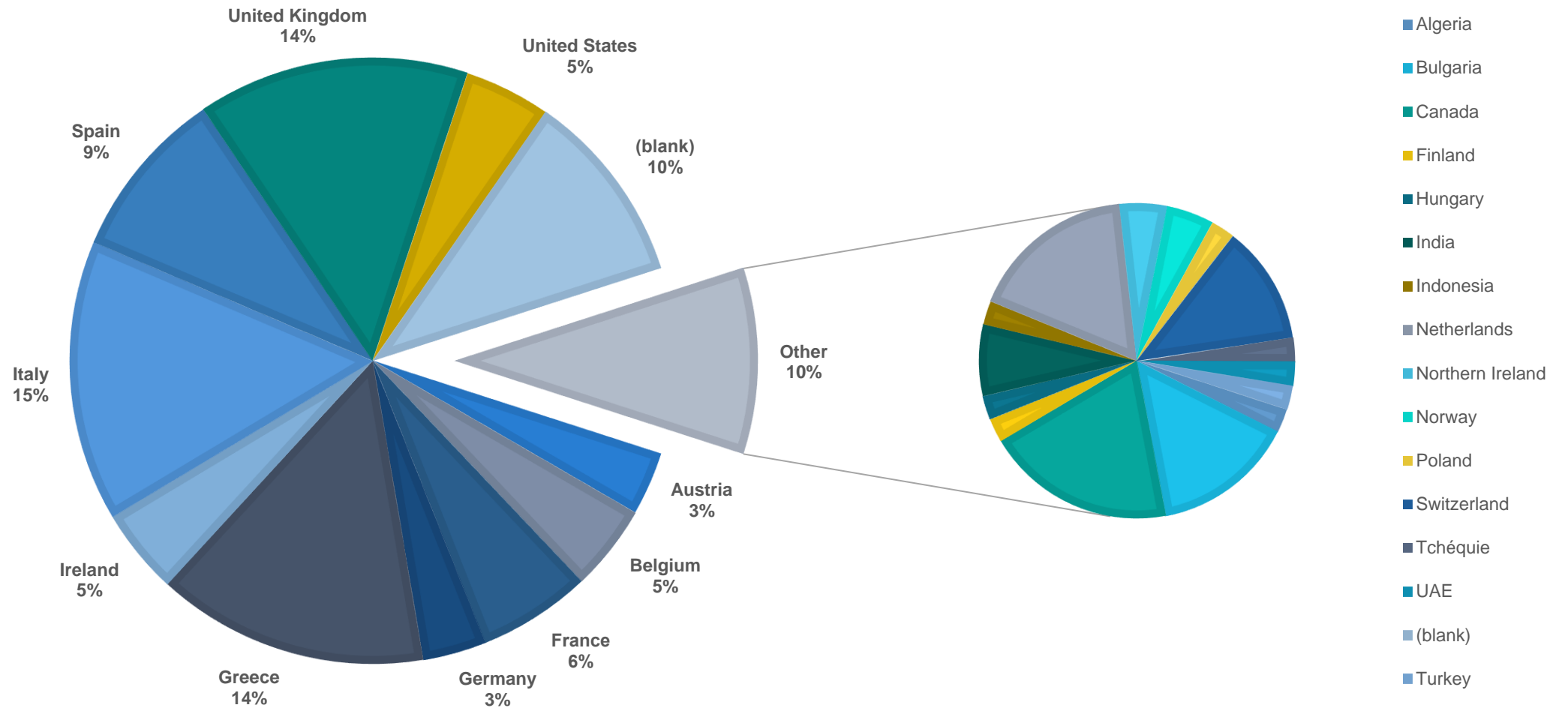
Of the 335 attendees that were present at any of the live sessions and/or accessed the Summit platform **61% were either Patients or Caregivers**. This confirms the PF Summit as a Patient Summit.

The next page shows a graphic representation of the country distribution of the active attendees with Italy having the largest representation (15%) followed by the United Kingdom (14%) and Greece (14%).

STAKEHOLDER DISTRIBUTION ACTIVE ATTENDEES



COUNTRY DISTRIBUTION ACTIVE ATTENDEES













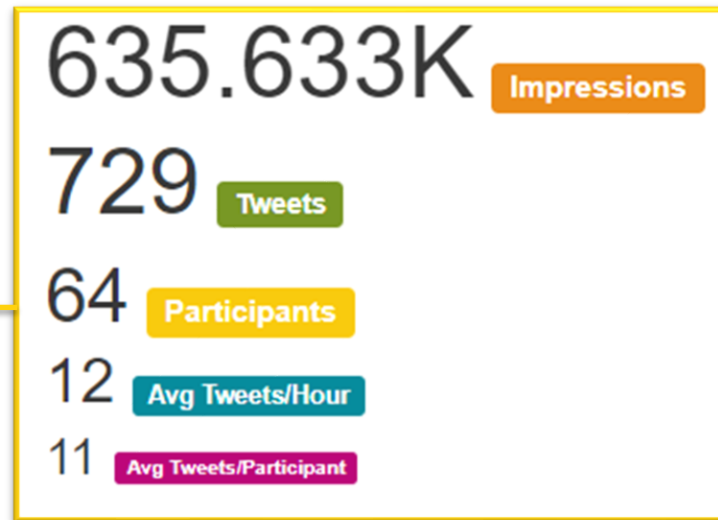
Review and metrics of the PF Summit Social Media footprint



The #PFSUMMIT21 metrics

Top 10 Influential

-  @EU_IPFF 100
-  @ActionPFsteve 72
-  @ActionPFcharity 68
-  @IPFthurles 61
-  @TriathARon 57
-  @flewett 53
-  @ILFA_Ireland 45
-  @GalapagosGlobal 40
-  @anmari_russell 39
-  @OrphaLung 38



@EU_IPFF had the highest impressions with 385.1K

Twitter data from the #PFSUMMIT21 hashtag from Fri, April 23rd 2021, 5:00AM to Sun, April 25th 2021, 5:00PM (Europe/Madrid)

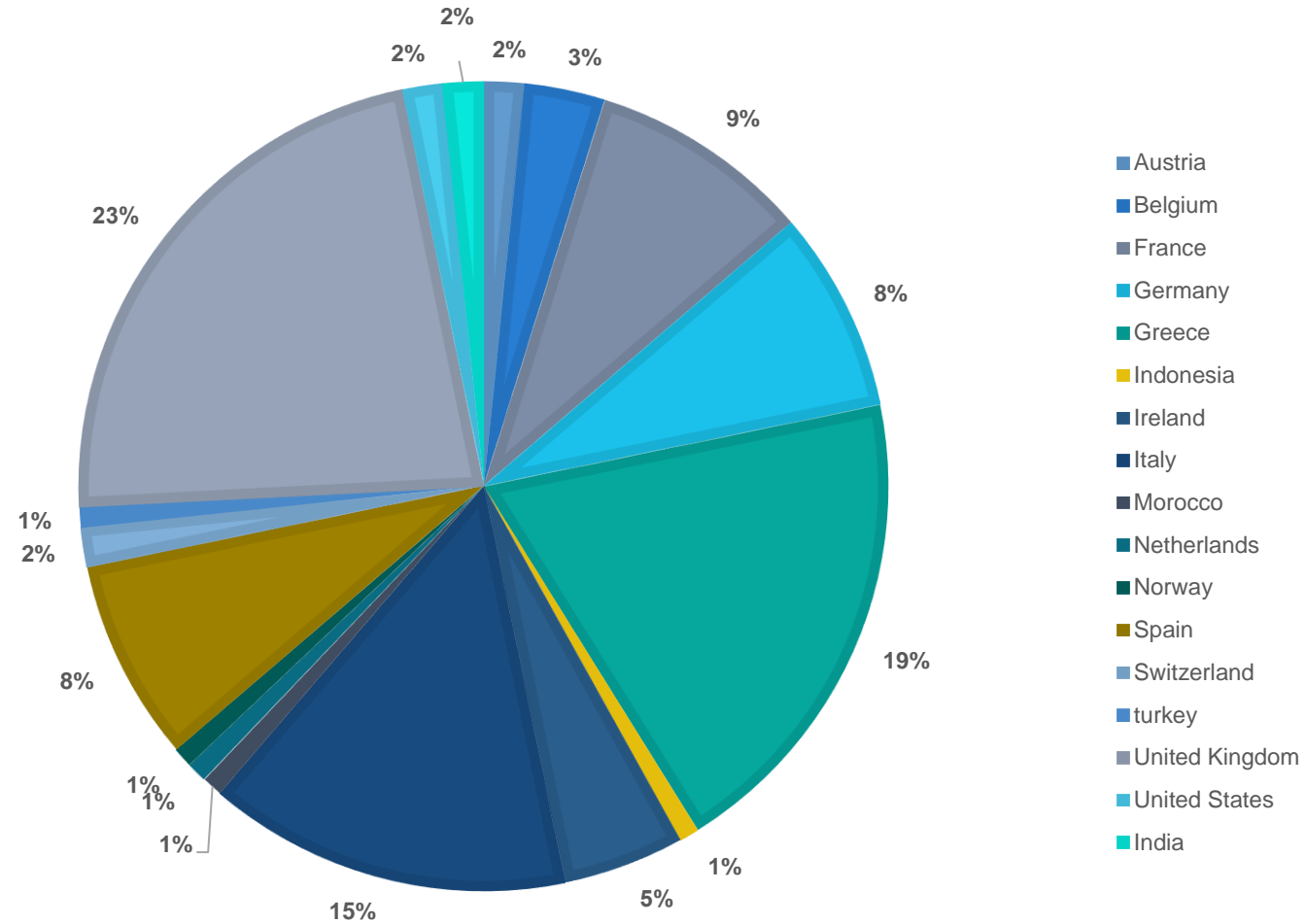


Review of the PF Summit Attendee Survey

127 responses



COUNTRY DISTRIBUTION OF ATTENDEES COMPLETING THE SURVEY



The graph shows the distribution of the attendees that completed the survey by country.

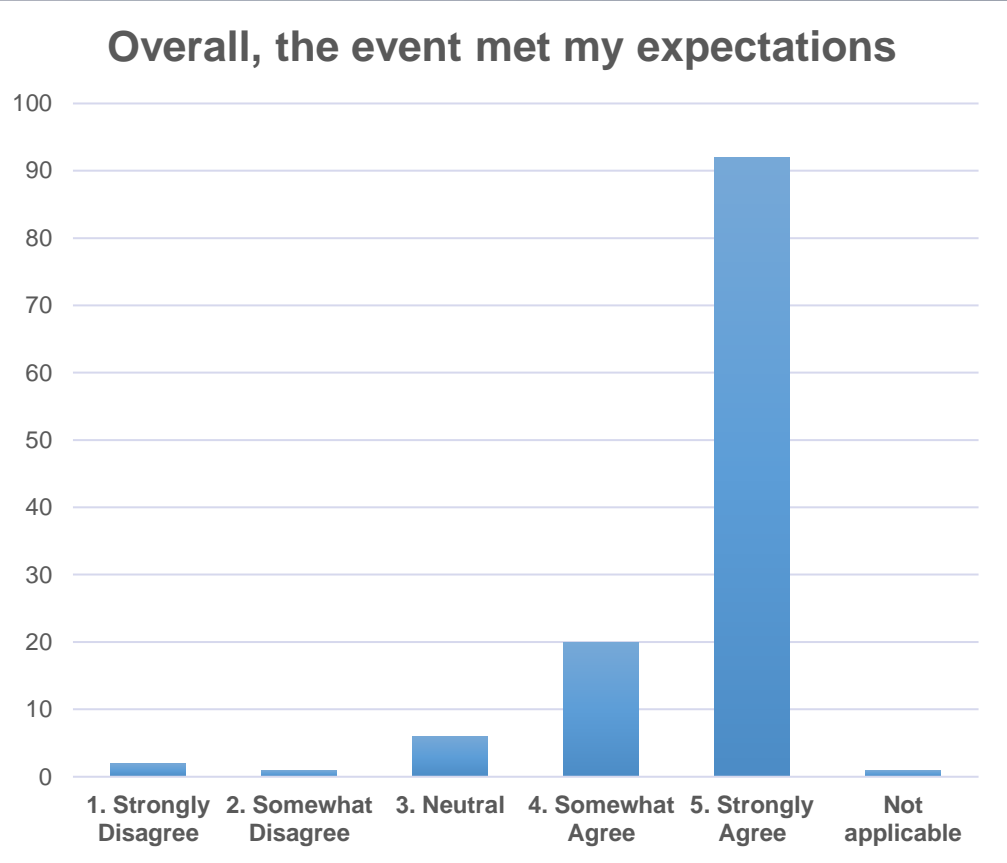


Overall Attendee Feedback

72.4% of the surveyed attendees confirmed that the Summit strongly met their expectations.

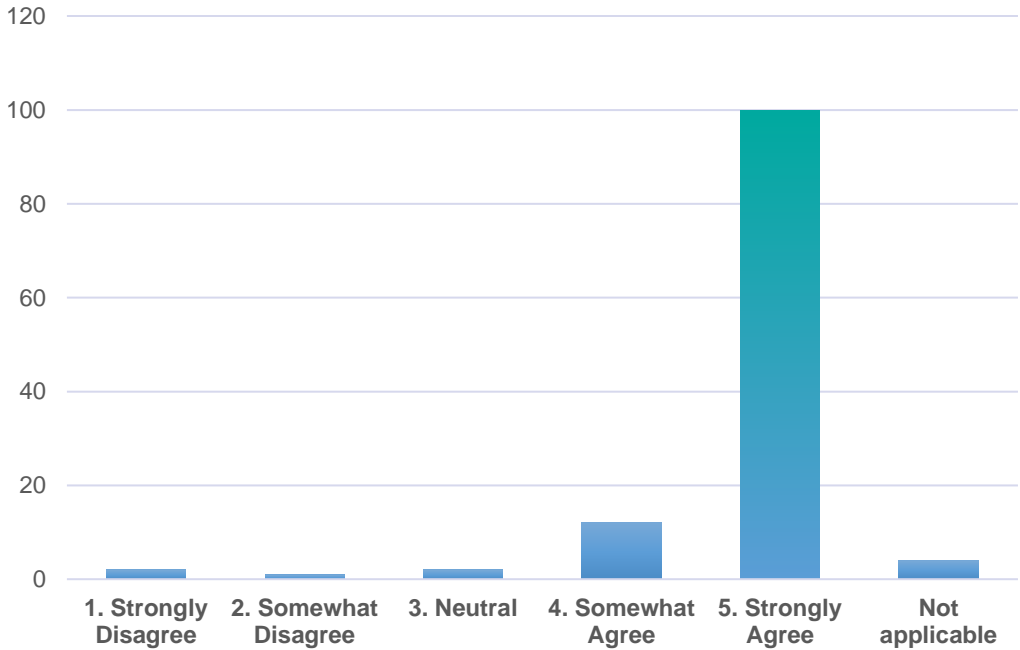
61.3% of the surveyed attendees confirmed that they learned new information which they can apply to their daily work.

75% of the surveyed attendees confirmed the meaningfulness of hearing from patients' perspective.

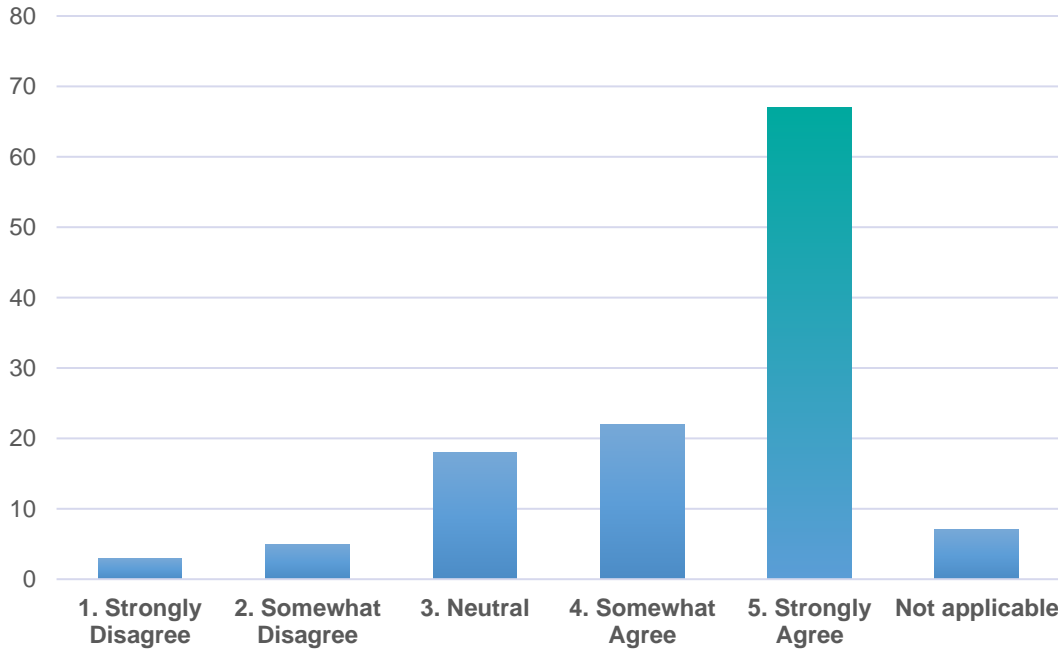


Overall Attendee Feedback – Virtual vs Face-to-Face Summit

If the EU-IPFF hosted another virtual Patient Summit, I would plan to attend



If the EU-IPFF hosted another face-to-face Patient Summit, I would plan to attend



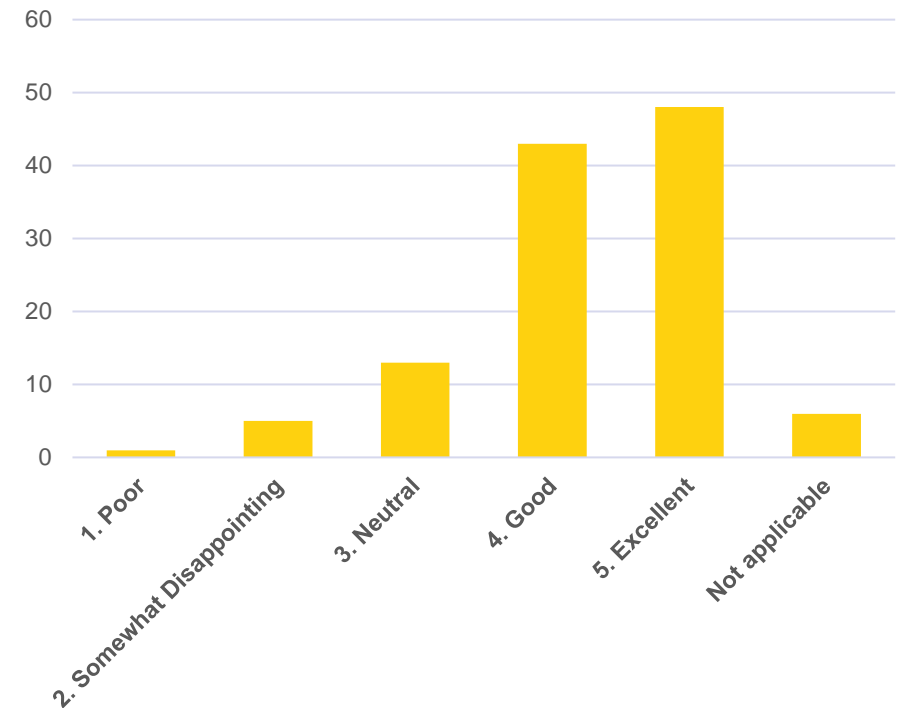
82.6% of the surveyed attendees confirmed that they would attend another virtual summit compared to 54.9% on a face-to-face setting



Overall Attendee Feedback – Logistics

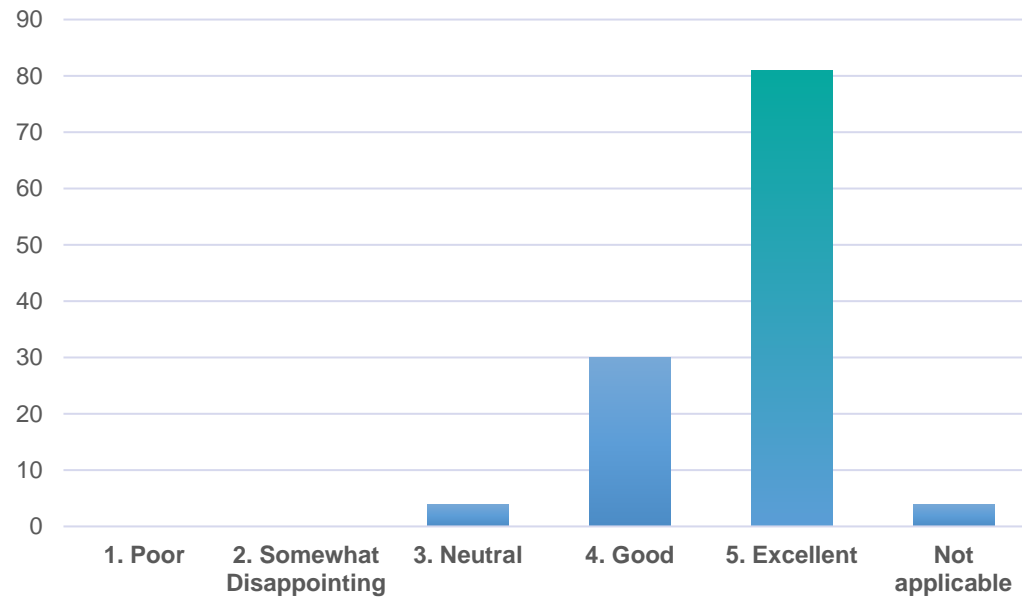
- 66.94% of the surveyed attendees found the registration process for the Summit *excellent* compared to 21.49% that thought it was *good*.
- 61.34% of the surveyed attendees thought the Summit platform was *excellent* compared to 31.09% that thought it was *good*.
- 41.38% of the surveyed attendees found the Q&A *excellent* and 11.21% found it *neutral*.
- Of those using the live translation (62 answers) 41.9% found the quality of the interpretation *excellent* while 11.3% of them thought it was somewhat disappointing.

Question & Answer and Chat used during the Summit

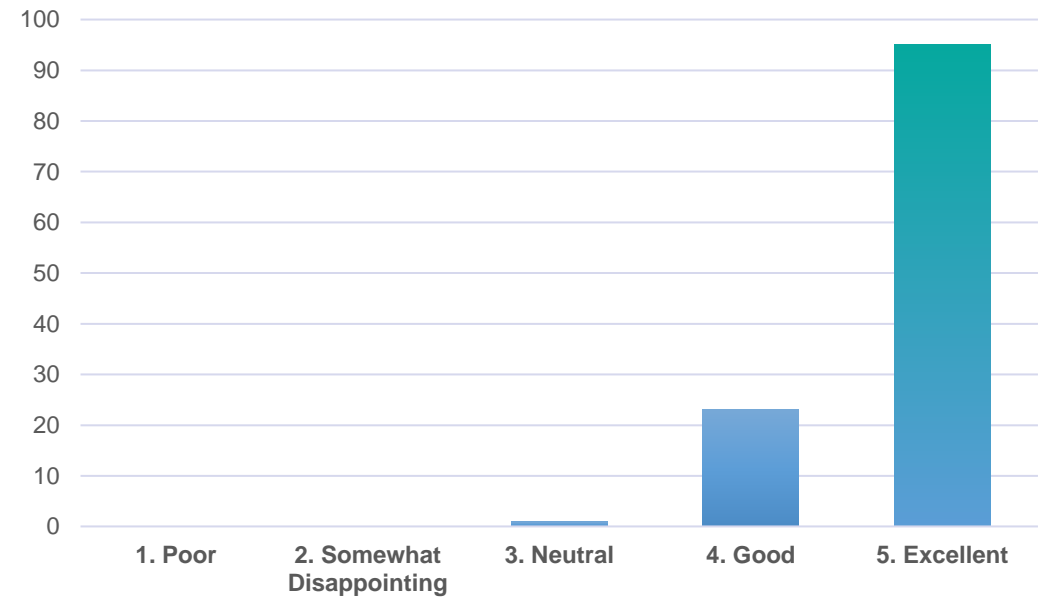


Overall Attendee Feedback - Logistics

Meeting organisation



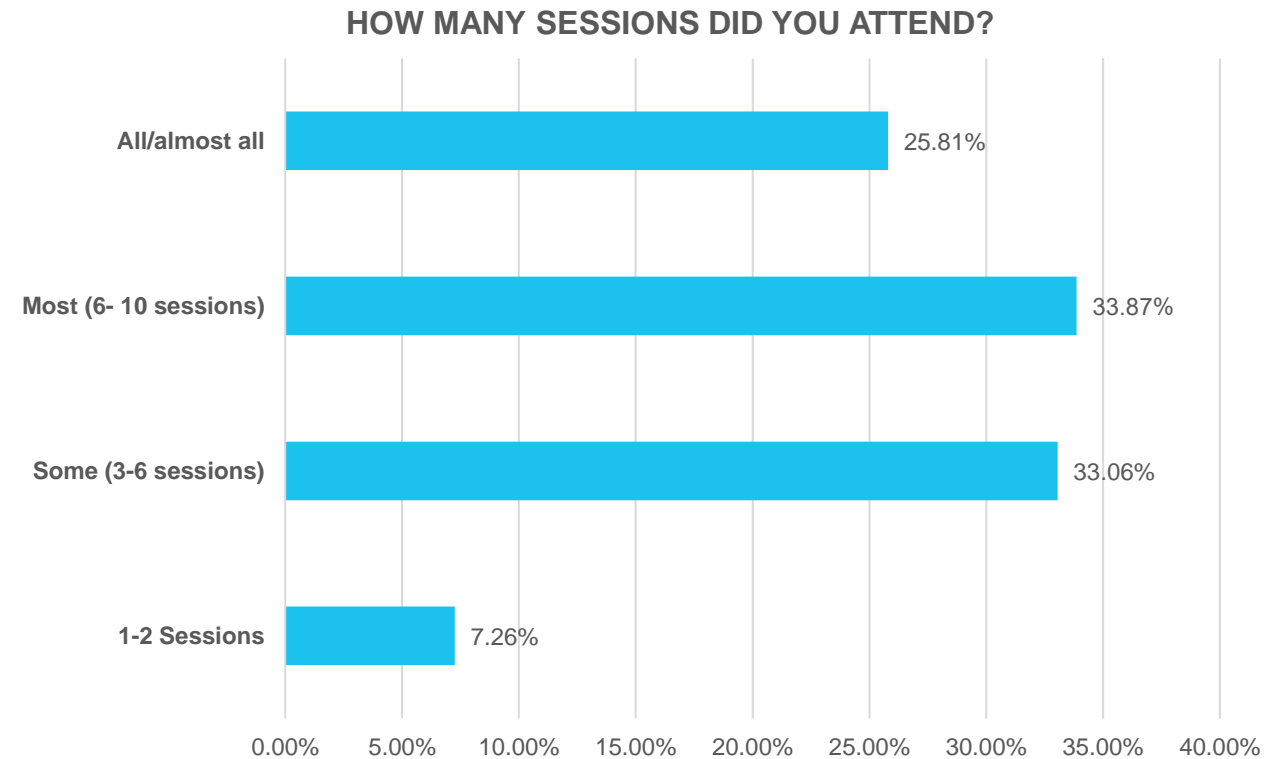
Overall impression of the Summit



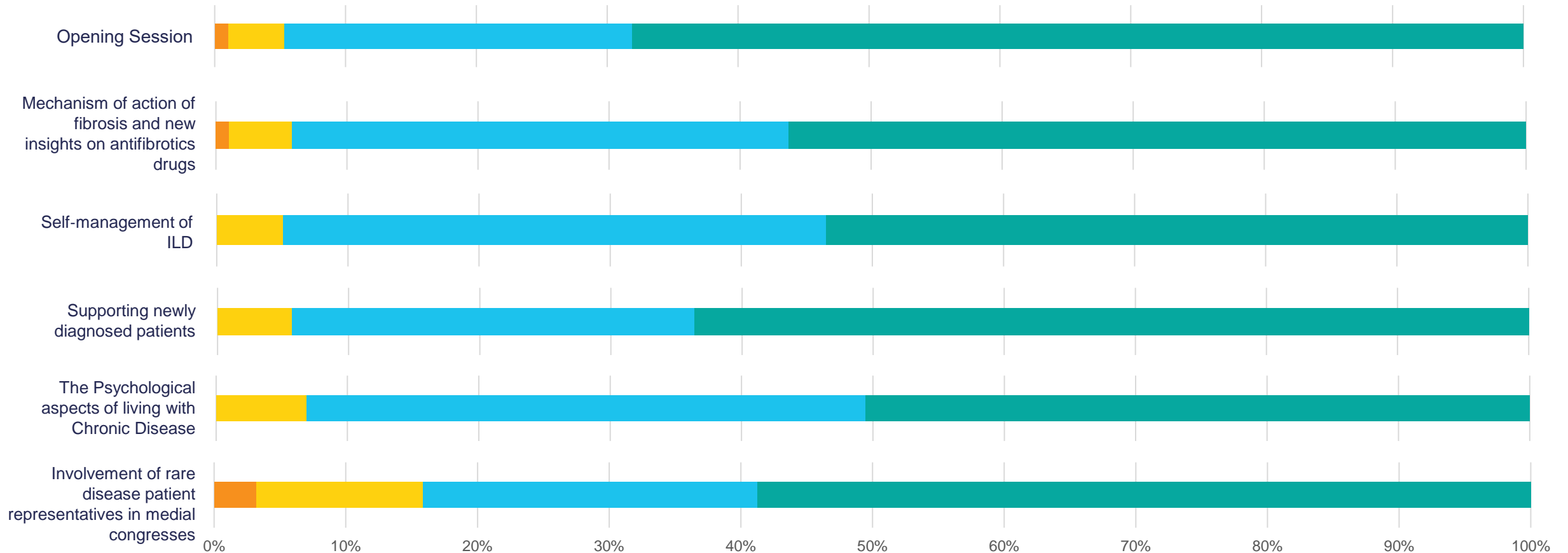
Attendee Feedback – Live Sessions

Most of the surveyed attendees confirmed having attended between 3 and 10 sessions (of a total of 15 sessions).

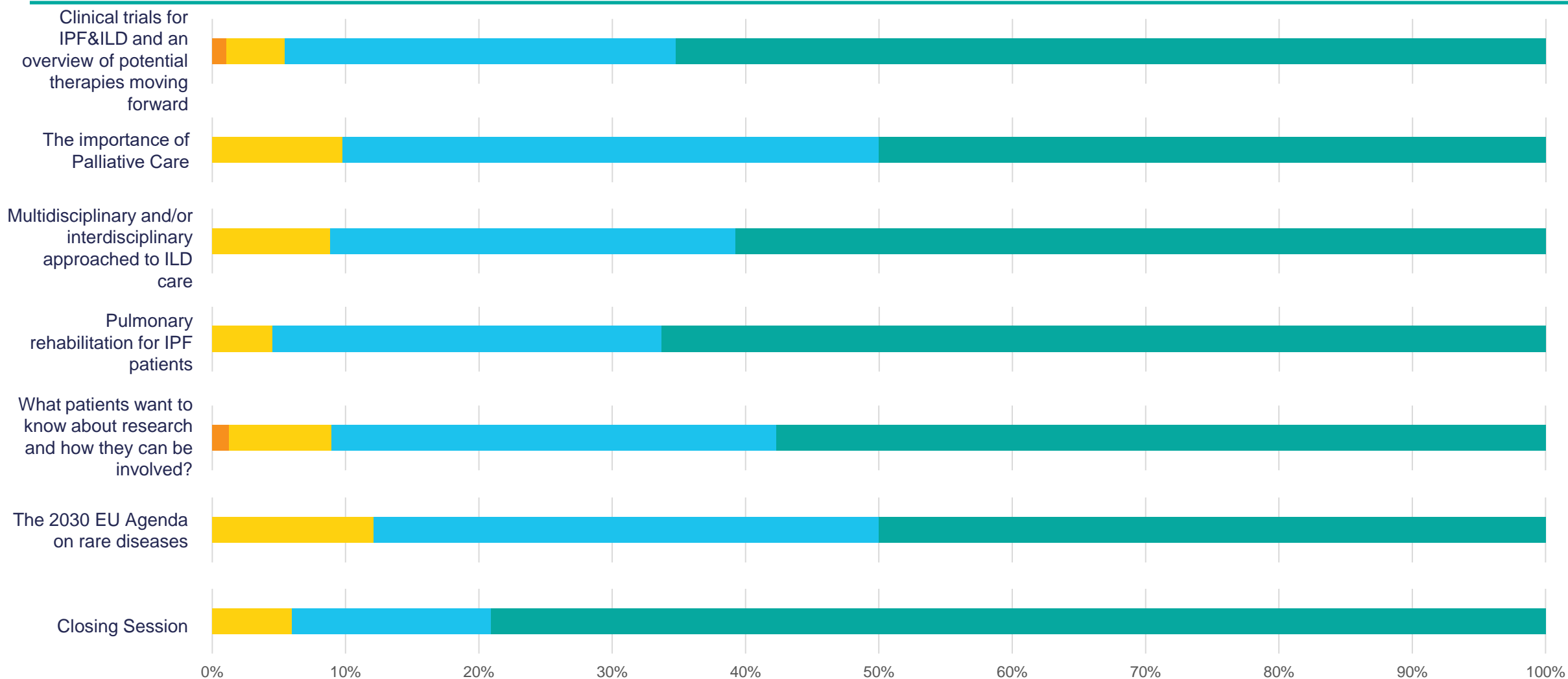
25.8% of surveyed attendees confirmed having attended all or almost all the sessions



Attendee Feedback – Live Sessions Rating



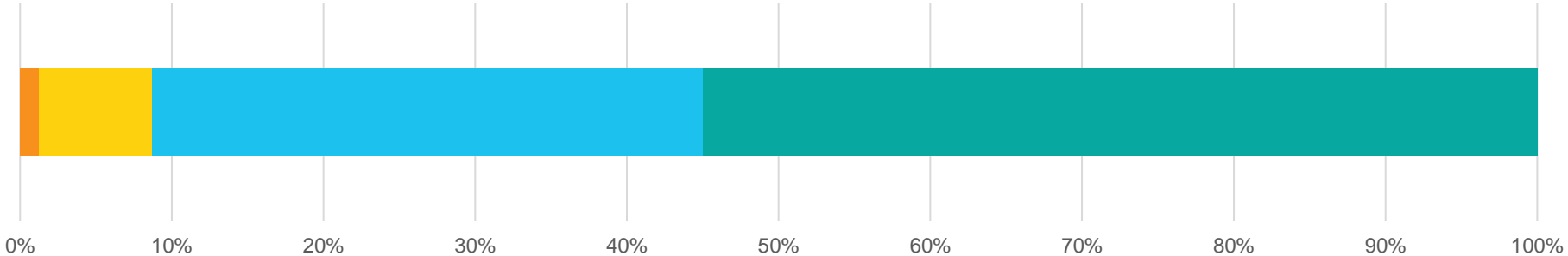
Attendee Feedback – Live Sessions Rating



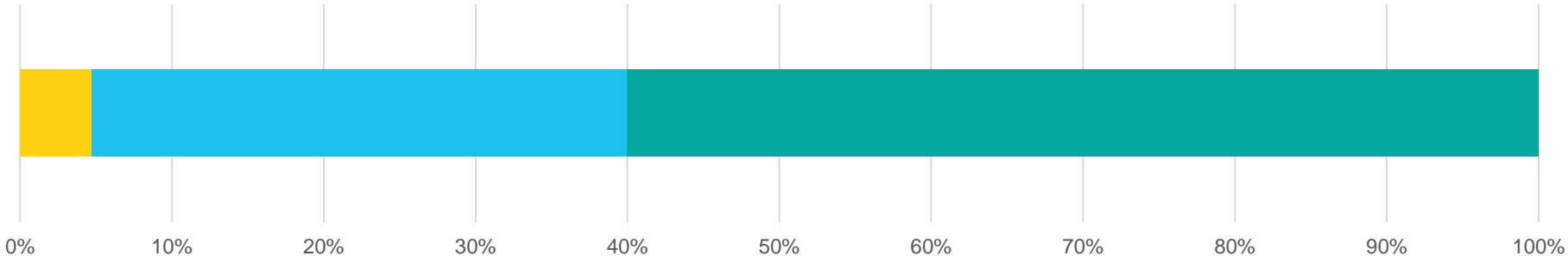
Attendee Feedback – Industry symposium Rating



Breaking barriers:
How to optimize
communication
between physicians,
patients and loved
ones



improving the path to
diagnosis in Europe:
the doctor, patient
and caregiver's
perspective



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